DOCUMENT RESUME

ED 321 453 EC 231 573

TITLE	Transition from Pediatric to Adult Health Care for Youth with Disabilities and Chronic Illnesses. CYDLINE Reviews.
INSTITUTION	Minnesota Univ., Minneapolis. National Center for Youth with Disabilities.; Society for Adolescent Medicine, Granada Hills, CA.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE	Jul 89
GRANT	MCJ27361-010
NOTE	16p.
AVAILABLE FROM	National Center for Youth with Disabilities, University of Minnesota, Box 721-UMHC, Harvard St. at East River Rd., Minneapolis, MN 55455.
PUB TYPE	Reference Materials - Bibliographies (131)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Chronic Illness; Delivery Systems; Foreign Countries; Health; *Health Programs; *Medical Services; Pediatrics; *Special Health Problems; Transitional Programs; *Young Adults
IDENTIFIERS	United Kingdom

ABSTRACT

The annotated bibliography is intended to give health care providers and planners background information and other resources on health transition issues for young adults with chronic health conditions. The 23 bibliographic citations date from 1972 to 1989 and are grouped into the following categories: U.S. demographics and health services utilization, empirical research on health outcomes, editorials and program descriptions, and health care in the United Kingdom. In addition, eight programs are described with information provided on: program name, contact person(s), affiliation, address, and phone number. Key words and a narrative abstract of the program complete the description. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

National Center for Youth with Disabilities

A national center to improve services for youth with disabilities

CITELINE Rec. 0998

Transition From Pediatric to Adult Health Care For Youth with Disabilities and Chronic Illnesses

July, 1989

A collaborative project of the

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Gayle Gabes
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. The Center is supported through a grant from the Bureau of Maternal and Child Health and Resources Development, Division of Services for Children with Special Health Needs, Department of Health and Human Services, #MCJ27361-010. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.

For additional information on the Society for Adolescent Medicine, contact:

Society for Adolescent Medicine
10727 White Oak Avenue
Suite 101
Granada Hills, CA 91344
818/368-5996

For additional information on the National Center for Youth with Disabilities, contact:

National Center for Youth
with Disabilities
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
1-800-333-6293 or 612/626-2825

National
Center for

Youth with Disabilities

October, 1989

Dear Colleague:

The National Center for Youth with Disabilities (NCYD) is pleased to send you this bibliography, *Transition from Pediatric to Adult Health Care for Youth with Chronic Illnesses and Disabilities*. Funded by a grant from the Bureau of Maternal and Child Health and Resources Development, Department of Health and Human Services, NCYD's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation. In keeping with this mission, we are preparing a series of bibliographies targeted to specific groups. This bibliography is intended to give health care providers and planners background information and other resources on health transition issues for young adults with chronic conditions.

This bibliography represents a very small portion of the wide range of interdisciplinary information found in the NCYD Resource Library. For a modest fee, you can request a search on any psychosocial topic related to youth with disabilities (e.g., sexuality, independent living, family issues). Alternatively, the computerized database is directly accessible through a microcomputer and modem.

We invite you to copy this bibliography and forward it to anyone you think could benefit. In approximately one month, we will send a short evaluation form to determine how useful this bibliography was to you.

An extensive search of the published literature found very few articles or books on the topic of the transition from pediatric to adult health care for youth with disabilities. If you are aware of any other materials or programs that we have overlooked, please bring them to our attention so that we can keep this information set as complete as possible.

If you would like to request an individualized search of the Resource Library, or if you have further questions, please call us at 1-800-333-NCYD.

Sincerely,

Gayle Geber

Gayle Geber
Program Director
National Center for Youth
with Disabilities

A. BIBLIOGRAPHIC MATERIALS

UI = Unique identifier assigned to each reference.
AU = Up to three authors (last name and initials) are listed for journal articles, book chapters, or unedited books. If more than three individuals authored a document, "et al." appears after the first three names.
ED = Up to three editors (last name and initials) are listed for edited books or special journal issues. If more than three individuals edited a document, "et al." appears after the first three names.
BK = Title of book.
TI = Name of journal article or book chapter.
SO = Source: Journal title abbreviation or publisher of book, place of publication for books, date of publication, volume and issue number for journals, and pages.
KW = Keywords. Descriptive keywords list the primary intended audience(s) and the type(s) of document. Documents which report empirical research often have other information displayed describing the methodology. Topical keywords describe the type of illness or disability that is addressed as well as other topical descriptors.
AB = Abstract or significant findings.

1. U.S. Demographics and Health Services Utilization

UI-12685 - Bibliographic Citation
AU- American Academy of Pediatrics; Council on Child Health;
TI- Age limits of pediatrics.
SO- Pediatrics 1972 Mar;49(3):463;
KW- (descriptive); Primary intended audience: Health Practitioners; Type of Document: Commentary/editorial;
KW- (topical); Health concerns; Professional issues;
AB- Policy statement from the American Academy of Pediatrics stating that pediatric care can usually extend until the time the client reaches the age of 21 years.

UI-12782
AU- Council on Child & Adolescent Health;
TI- Age limits of pediatrics.
SO- Pediatrics 1988 May;81(5):736;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Commentary/editorial;
KW- (topical); Chronic illness, general; Health concerns; Treatment, intervention; Professional issues;
AB- This most recent statement from the American Academy of Pediatrics' Council on Child and Adolescent Health states that the upper age limit of pediatric care extends through age 21 except for youth with chronic illness or disability, in which case pediatric care may continue longer.

UI-12686 - Bibliographic Citation
AU- Resnick MD;
TI- Use of age cutoff policies for adolescents in pediatric practice: Report from the Upper Midwest Regional Physician Survey.
SO- Pediatrics 1983 Sep;72(3):420-7;
KW- (descriptive); Primary intended audience: Health Practitioners; Type of document: Empirical research; Type of research: Cross-sectional; Sample description: Clinics/hospitals; Urban; Suburban; Rural; Methodology: Interview with professional; Professional questionnaire/self-report; Study size: 476;
KW- (topical); Chronic illness, general; Health concerns; Needs assessment; Treatment, intervention; Professional issues;
AB- In this survey of community-based pediatricians, family practitioners, and general practitioners in the Upper Midwest (WI, MN, IA, ND, SD), it was found that many pediatricians did use age cutoffs in their practices, usually in mid to late adolescence. Most of these physicians, however, did grant exceptions to age cutoff policies, and 23% cited chronic illness as a reason for keeping the adolescent under pediatric care for a longer period of time.

UI-12687 - Bibliographic Citation
AU- Sanders JM Jr.;
TI- Health care delivery to adolescents and young adults by pediatricians.
SO- Pediatrics 1988 Sep;82(3 pt. 2):516-7;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Review, general; Commentary/editorial;
KW- (topical); Health concerns; Treatment, intervention; Organizations; Preservice training, education;
AB- After a review of studies assessing the degree to which pediatricians provide care to adolescents and young adults and an acknowledgement that pediatrics actively advocates for this population, the author concludes that pediatricians often do not provide such services and that pediatric residency training programs are deficient in their preparation of graduates to work in this area.

UI-12690 - Bibliographic Citation
AU- Newacheck P; McManus P;
TI- Fact sheet on adolescents with special health care needs: Prevalence, severity, utilization and insurance coverage.
SO- Unpublished 1989 Feb;:1-2;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research;
KW- (topical); Handicaps/DD, general; Chronic illness, general; Health concerns; Needs assessment; Economic issues;
AB- Based on analyses of the 1984 National Health Interview Survey, this fact sheet provides data on the 2 million (6%) adolescents 10-18 years of age who experience chronic health conditions which limit their usual activities (available for ordering from: McManus Health Policy, Inc., 4801 Massachusetts Ave. N.W., Suite 400, Washington, D.C. 20016; 202/895-1580.

UI-12009 - Bibliographic Citation
AU- Newacheck PW; Budetti PP; McManus P;
TI- Trends in childhood disability
SO- Am J Public Health 1984 Mar;74(3):232-6;
KW- (descriptive); Primary intended audience: Health practitioners; Researchers; Type of document: Empirical research;
KW- (topical); Chronic illness, General; Epidemiology;
AB- Analysis of National Health Interview Survey data finding almost a doubling of the proportion of children with activity limitations due to chronic illness from 1960-81.

UI-11824 - Bibliographic Citation
AU- Newacheck PW; Budetti PP; Halfon N;
TI- Trends in activity-limiting chronic conditions among children.
SO- Am J Public Health 1986 Feb;76(2):178-84;
KW- (descriptive); Primary intended audience: Health practitioners; Researchers; Type of document: Empirical research;
KW- (topical); Chronic illness, general; Attitudes toward people with disabilities; Epidemiology;
AB- Analysis of data from the National Health Interview Survey indicating an increase of prevalence of activity-limiting chronic conditions among children under 17 years from 1.8% in 1960 to 3.8% in 1981 with approximately 40% of the increase occurring before 1970. After 1970, the increase in prevalence was due to increases in the less-severe forms of limitations.

UI-11678 - Bibliographic Citation
AU- Carroll G; Massarelli E; Opzoomer A; et al.;
TI- Adolescents with chronic disease. Are they receiving comprehensive health care?
SO- J Adol Health Care 1983 Dec;4(4):261-5;
KW- (descriptive); Primary intended audience: Health Practitioners; Type of Document: Empirical research; Type of Research: Cross-sectional; Sample Description: Clinics/hospitals; Methodology: Youth questionnaire/self report; Study size: 61; Sample Age Range: 14-18;
KW- (topical); Diabetes mellitus; Epilepsy, seizure disorders; Asthma; Other circulatory, respiratory; Inflammatory bowel disease, Crohn's; Chronic illness, General; Renal disease; Needs assessment;
AB- Seventy-eight percent of these chronically ill adolescents considered their subspecialist to be their "personal" physicial, but only 27% reported that they discussed general health concerns with that physician. This sample of adolescents reported health concerns similar in nature but greater in number than those of "healthy" adolescents. Few problems were found regarding sexuality, alcohol, and other drug use.

UI-12689 - Bibliographic Citation
AU- Palfrey JS; Levy JC; Gilbert KL;
TI- Use of primary care facilities by patients attending specialty clinics.
SO- Pediatrics 1980 Mar;65(3):567-72;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research; Type of research: Cross-sectional; Sample description: Clinics/hospitals; Methodology: Interview with family member; Study size: 158;
KW- (topical); Diabetes mellitus; Epilepsy, seizure disorders; Asthma; Juvenile rheumatoid arthritis; Other musculatory, connective; Health concerns; Needs assessment; Treatment, intervention;
AB- Children and adolescents attending medical specialty clinics at the Children's Hospital Medical Center in Boston at least twice a year were studied regarding their health care services utilization. Those least likely to have a regular source of primary care were the adolescents and those who lived in the inner city. Forty-three percent of the adolescents (as reported by their parents) had no regular source of primary care.

UI-12688 - Bibliographic Citation
AU- Smyth-Staruch K; Breslau N; Weitzman M; et al.;
TI- Use of health services by chronically ill and disabled children.
SO- Med Care 1984 Apr;22(4):310-28;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research; Type of research: Cross-sectional; Comparison/control group used; Randomly selected; Sample description: Clinics/hospitals; Other study location; Study size: 825; Sample age range: 3-18;
KW- (topical); Handicaps/DD, general; Cystic fibrosis; Cerebral palsy; Spina bifida, myelodysplasia, meningomyelocele; Treatment, intervention; Program development;
AB- Hospitalization and outpatient health care services were compared between 369 chronically ill patients and a "normal" comparison group of 456 children and adolescents. The use of these services was 10 times higher in the chronically ill group, particularly for physician specialists, occupational and physical therapists, and school nurses. The majority of the health care services received by the chronically ill group was accounted for by a minority of the children. Estimated expenditures were also much greater for the children with chronic illnesses.

2. Empirical Research on Health Outcomes

UI-12506 - Bibliographic Citation
AU- Salmi J; Huupponen T; Oksa H; et al.;
TI- Metabolic control in adolescent insulin-dependent diabetics referred from pediatric to adult clinic.
SO- Ann Clin Res 1986 ;18(2):84-7;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research; Type of research: Longitudinal; Prospective; Sample description: Clinics/hospitals; Methodology: Physical examination; Study size: 61; Sample Age Range: 16-18;
KW- (topical); Diabetes mellitus; Compliance, therapeutic alliance; Gender issues; Physical (puberty) development; Social, psychological development; Individual assessment, diagnosis; Treatment, intervention; Case management;
AB- This study looked at metabolic control before, during, and after adolescent transfer from treatment through pediatric services to treatment through adult services. Findings indicated that, among older adolescents, this change in treatment context reduces metabolic control in the short term but increases it in the long term. The authors caution that such patients be well prepared. They conclude from the data that patients with a shorter disease history and boys cope better with the transition. They suggest that decisions regarding such a change in treatment context be determined individually, based on level of pubertal and social maturation.

3. Editorials and Program Descriptions

UI-12679 - Bibliographic Citation
AU- Berg P;
BK- Youth in Transition: Developing Appropriate Services for Adult Survivors of Pediatric Disorders - Summary of Proceedings.
SO- National Center for Youth with Disabilities; National Center for Networking Community Based Services: NCYD, Box 721 UMHC, Harvard at E. River Rd., University of Minnesota, Minneapolis, Minnesota;1988:12;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Descriptive, case studies;
KW- (topical); Handicaps/DD, general; Health concerns; Needs assessment; Treatment, intervention; Program development; Teaming;
AB- The purpose of this conference was to establish a national network that would promote the development of state and community-based models of comprehensive coordinated planning and health service delivery for youth with disabilities and their families. This working conference brought together delegations from five states (CO, MN, VA, WA, WI) to develop strategies to ensure transition to adult care for survivors of pediatric health disorders. These proceedings include a listing of each state's strengths, weaknesses, foci, potential roles for the private and public sectors, and goals or activities.

UI-12674 - Bibliographic Citation
AU- Garson A;
TI- The science and practice of pediatric cardiology in the next decade.
SO- Am Heart J 1987 Aug;114(2):462-8;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Review, general; Commentary/editorial;
KW- (topical); Congential heart defect; Rheumatic heart disease; Health concerns; Treatment, intervention; Professional issues; Preservice training, education; Continuing training, education;
AB- Within a general discussion of the future role of pediatric cardiology, the author speaks to the need of pediatric cardiologists to see young adults indefinitely to keep their client load up, to fill the void in the adult caregiving system, and to be advocates for this group of patients as their longterm problems would remain under the pediatric cardiologist's purview with an expanded knowledge of and training in adult health needs.

UI-12675 - Bibliographic Citation
AU- Allen HD;
TI- The adolescent and young adult with heart disease.
SO- Am J Dis Child 1985 Oct;139(10):976;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Commentary/editorial;
KW- (topical); Congential heart defect; Rheumatic heart disease; Contraception; Pregnancy, abortion, childbirth; Employment, career planning; Health concerns; Treatment, intervention; Economic issues;
AB- Following a short discussion of problems for young adults with cardiac problems regarding health insurance, vocational choice, unnecessary restrictions on physical activity levels, contraception, and pregnancy, the author raises questions regarding health care delivered by pediatric or adult care providers stressing the need for an individualized approach to transitioning to adult health care.

UI-12676 - Bibliographic Citation
AU- Cameron JS;
TI- The continued care of pediatric patients with renal disease into adult life.
SO- Am J Kidney Dis 1985 Aug;6(2):91-5;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Review, general;
KW- (topical); Renal Disease; Health concerns; Treatment, intervention; Teaming; Preservice training, education; Continuing training, education;
AB- This article outlines which children require follow-up through adolescence or into adulthood and discusses practical problems in transferring care to adult providers including: the recognition that a problem with prolonged pediatric care exists, communications between pediatric and adult providers, loss to follow-up, and transition planning. Also discussed is the timing of transfer to the internist/nephrologist, and suggestions for professional training are made.

UI-12683 - Bibliographic Citation
AU- Hull R;
TI- Care of physically handicapped young adults (letter)
SO- Br Med J 1988 Jun;296(6638):1739;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Commentary/editorial;
KW- (topical); Handicaps/DD, general; Juvenile rheumatoid arthritis; Health concerns; Treatment, intervention;
AB- In this short letter to the editor regarding the need for appropriate health care for young adults, the author notes the problem of identifying the need for change in a context of chronicity.

UI-12682 - Bibliographic Citation
AU- Moore IM; Klopovich P;
TI- Future perspectives
SO- Semin Oncol Nurs 1989 Feb;5(1):70;
KW- (descriptive); Primary intended audience: Health Practitioners; Type of document: Commentary/editorial;
KW- (topical); Neoplasms (Cancer); Health concerns; Case management;
AB- In this issue of the journal devoted to the long term aspects of cancer, this summary statement identifies nurses as the professionals who will likely be responsible for the transition from pediatric to adult health care for cancer survivors who develop second malignancies.

UI-12504 - Bibliographic Citation
AU- Delengowski A; Dugan-Jordan M;
TI- Care of the adolescent cancer patient on an adult medical oncology unit.
SO- Semin Oncol Nurs 1986 May;2(2):95-103;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Descriptive, case studies;
KW- (topical); Neoplasms (Cancer); Death, dying; Locus of control, independence; Individual stress, coping, social supports; Peer relations, communication; Developmental processes; Family relationships, communication; Treatment, intervention; Confidentiality, communication; Continuing training, education;
AB- This article uses several case studies to illustrate the issues involved in adolescent cancer treatment, particularly in an adult oncolgy unit. Normative adolescent development and behavior are outlined. Nursing strategies are recommended. Dependence, interdependence, and independence are seen as central themes. The relationship between the adolescent and his/her family and that between the adolescent and his/her caregivers is stressed. Treatment on an adult unit is seen as particularly stressful due to: staff lack of knowledge and experience with adolescents and patient isolation from adolescent peers. DRGS are held responsible for much of the shift in adolesent care to adult units.

UI-12677 - Bibliographic Citation
AU- Gobel B;
TI- Educational preparation for the nursing staff on a combined pediatric/adult bone marrow transplant unit.
SO- J Assoc Pediatr Oncol Nurses 1988 ;5(1-2):35;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Descriptive, case studies;
KW- (topical); Neoplasms (Cancer); Health concerns; Treatment, intervention; Continuing training, education;
AB- Using a philosophy of family-centered care on a combined pediatric and adult bone marrow transplant unit, the author outlines the workshops used in continuing nursing education.

4. Health Care in the United Kingdom

UI-12684 - Bibliographic Citation
AU- Bax MCO; Smyth DPL; Thomas AP;
TI- Health care of physically handicapped young adults.
SO- Br Med J 1988 Apr;296(6630):1153-5;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research; Type of research: Cross-sectional; Sample description: Clinics/hospitals; Community social service agencies; Methodology: Physical examination; Interview with youth; Study size: 111; Sample age range: 18-25;
KW- (topical); Moderate handicap; Severe handicap; Cerebral palsy; Hearing impairment; Spina bifida, myelodysplasia, meningomyelocele; Multiple sclerosis; Circulatory, respiratory system diseases; Scoliosis; Other congenital anomalies; Muscular dystrophy; Mild retardation; Moderate retardation; Health concerns; Needs assessment; Treatment, intervention;
AB- This needs assessment, conducted in London and Buckinghamshire, England, identified the health needs of a group of young adults with moderate to severe disabilities. Generally, the health status of these individuals was poor. Less than one-third were receiving appropriate health care. Regular health care declined greatly after they left school and the health care access it afforded.

UI-12678 - Bibliographic Citation
AU- Benjamin C;
TI- The use of health care resources by young adults with spina bifida.
SO- Z Kinderchir 1988 Dec;43(Suppl. 2):12-4;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research; Type of research: Cross-sectional; Sample description: Clinics/hospitals; Methodology: Interview with youth; Study size: 21; Sample age range: 17-21;
KW- (topical); Spina bifida, myelodysplasia, meningomyelocele; Health concerns; Needs assessment;
AB- This study, conducted in England, examined many facets of health care for young adults with spina bifida: current and past hospital supervision, the role of general practitioners, community nursing services, contact with other health workers, morbidity, satisfaction with health service, and dependence. Many of these young adults experienced a reduction in hospital based and community health services upon leaving the pediatric system. Fifty-two percent were dissatisfied with their current health care.

UI-12681 - Bibliographic Citation
AU- Parker G; Hirst M;
TI- Continuity and change in medical care for young adults with disabilities.
SO- J R Coll Physicians Lond 1987 Apr;21(2):129-33;
KW- (descriptive); Primary intended audience: Health practitioners; Type of document: Empirical research; Type of research: Cross-sectional; Sample description: Clinics/hospitals; Methodology: Interview with family member; Study size: 291; Sample Age Range: 18-22;
KW- (topical); Moderate handicap; Severe handicap; Schizophrenia, psychosis, autism; Cerebral palsy; Epilepsy, seizure disorders; Spina bifida, myelodysplasia, meningomyelocele; Muscular dystrophy; Other genetic; Moderate retardation; Severe retardation; Health concerns; Needs assessment; Treatment, intervention; Program development;
AB- While many young adults in this sample from the United Kingdom experienced decreased medical consultation upon leaving the child health care system, particularly those with multiple impairments, the primary conclusion drawn from the study indicated that most caregivers of the young adults felt a strong need for the ongoing medical support and guidance received when their children were younger. Examples of model health care facilities for young adults are outlined.

UI-11347 - Bibliographic Citation
AU- Thomas A; Bax M; Coombes K; et al.;
TI- The health and social needs of physically handicapped young adults. Are they being met by the statutory services?
SO- Dev Med Child Neurol 1985 Aug;27(4):Suppl 50;
KW- (descriptive); Primary intended audience: Health practitioners; Mental health, social workers; Type of document: Review, general;
KW- (topical); Handicaps/DD, general; Cerebral palsy; Spina bifida, myelodysplasia, meningomyelocele; Musculoskeletal, connective system diseases; Muscular dystrophy; Family relationships, communication; Socioeconomic status, financial resources; Sexuality; Education; Employment and vocational rehabilitation; Recreation, leisure, sports, arts; Needs assessment; Economic issues; Planning issues; Policy issues; Entitlement issues;
AB- This monograph analyzes the availability and adequacy of comprehensive services for young adults, especially those with cerebral palsy, spina bifida, or muscular dystrophy. The authors review studies of orthopedic problems, speech problems, incontinence, dental health, sexuality, psychosocial adjustment, education, employment, economic support, recreation, and social support. Although specific to the United Kingdom, there are implications for youth with disabilities in transition to adulthood in any country.

B. PROGRAM DESCRIPTIONS

NM = Name of the program.
CT = Contact person(s).
AF = Affiliation.
AD = Address.
PH = Phone number.
KW = Keywords. Descriptive keywords describe the scope of the program, the population served, the types of services provided, the times of year the program is operational, the focus of the program, and whether or not it publishes a newsletter regarding youth with disabilities. Topical keywords describe the chronic illnesses or disabilities that are addressed.
AB = Narrative abstract of program.

UI-10028 - Programs/Projects
NM- The Bridge Program - Adolescent to Adult
CT- Schidlow Dan, MD; Fiel Stanley, MD
AF- Temple University Hospital
AD- Broad & Ontario Streets, Philadelphia, PA 19140
PH- 215/221-3332
KW- (descriptive); Scope of program: Local: PA; Population served: Urban; Types of services provided: Direct service; I&R fees negotiable; Does charge a fee for consultative services; Fees for consultative services are negotiable; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Hospital-based specialty care; Interagency collaboration; Does publish newsletter regarding youth with disabilities;
KW- (topical); Cystic fibrosis;
AB- Current project was developed to study the issue of transitioning in the health care delivery system. The goal was to develop an appropriate adult health care delivery model and study this process and the process of transitioning patients from a pediatric hospital to an adult hospital in separate locations. Objectives of the project are to examine the following four issues: 1) effect of transition on patients and their families; 2) determining services needed in the adult care setting to provide appropriate care; 3) determining whether interinstitutional issues can be overcome to develop such a program and 4) studying financial impact on patients and institutions.

UI-10240 - Programs/Projects
NM- Adolescent Health Program
CT- Farrow J., MD or West M., Ph.D.
AF- University of Washington
AD- Adolescent Clinic/WJ-10, University of Washington, Seattle, WA 98195
PH- 206/545-1273
KW- (descriptive); Scope of program: Multi-state regional: Washington, Alaska, Idaho, Oregon; Population served: Urban; Suburban; Types of services provided: Direct service; Information and referral; Consultation; Teaching; Research; No fee for I & R; Does not charge a fee for consultative services; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Mental health; Nutrition; Education; Vocational and career services; Independent living; Social services; Advocacy; Policy and planning, general; Interagency collaboration; Psycho-social issues; Developmental processes; Family; Does not publish newsletter regarding youth with disabilities;
KW- (topical); Mild handicap; Chronic illness, general;
AB- Multidisiplinary team approach to young adults 16-24 with chronic conditions to assess needs (personal and family), advocate for needed community services (eg DVR, DDD) and facilitate transition to adult health care systems.

UI-10032 - Programs/Projects
NM- Transitional Adolescent Diabetes Program
CT- Orr Donald, M.D.; Gray Deborah, R.N.
AF- Indiana University
AD- Riley Hospital, Department of Pediatrics, A-580, 702 Barnhill Road, Indianapolis, IN 46223
PH- 317/274-8812
KW- (descriptive); Scope of Program: Multi-state regional: IN, KY, IL; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Teaching; Research; Operational entire year (12 months); Description of focus of program: Hospital-based specialty care; Nutrition; Vocational and career services; Vocational rehabilitation; Independent living; Social services; Interagency collaboration; Does not publish newsletter regarding youth with disabilities;
KW- (topical); Diabetes mellitus;
AB- This is an interdisciplinary demonstration project to deliver and model developmentally appropriate diabetes related care for young adults and their families. The clinic serves as a training site for residents in pediatrics and internal medicine and for clinical research and transitional issues. It focuses specific attention on vocation/education/career, transition into the adult health care system.

UI-10008 - Programs/Projects
NM- Young People with Physical Disabilities Program (YPPD)
CT- Shapiro Don or DeRosa Thomas
AF- The Door--A Center of Alternatives
AD- 618 Avenue of the Americas, New York, NY 10011
PH- 212/691-6161
KW- (descriptive); Scope of program: Local: NY; Population served: Urban; Types of services provided: Direct service; Information and referral; Consultation; No fee for I & R; Operational entire year (12 months); Description of focus of program:Primary health care or hospitalization; Mental health; Nutrition; Other health related program focus: Sexual health; health promotion; Education;Vocational and career services; Independent living; Social services; Sexuality; Recreation, leisure; The arts; Law; Advocacy; Interagency collaboration; Psychosocial issues; Other: Substance abuse, prevention/treatment; Does publish newsletter regarding youth with disabilities;
KW- (topical); All chronic illness or disability; Affective, emotional disorders; suicide; Attention-deficit disorders, hyperactivity; Other mental, emotional disorders; Circulatory, respiratory system diseases; Musculoskeletal, connective system diseases; Congenital anomalies; Muscular dystrophy; Trauma;
AB- The Door's "Young People with Physical Disabilities Program" is a model project now in its fourth year in which inner-city adolescents between 12-21 with various physical and sensory disabilities are integrated into the Door's mental health, health, educational, vocational, artistic, and social services, programs and workshops. In the YPPD, youth mainstream alongside their non-disabled peers accessing the total comprehensive service center. A special project focusing on Transitional and Independent Living skills, including O.T., transportation training, goal-setting/ decision making was added this past year.

0UI-10037 - Programs/Projects
NM- Adolescent-Adult Transition Program
CT- Sugioka Mary, M.D.
AF- Clinical Center for the Study of Development and Learning
AD- Center for Development and Learning, BSRC 220-H, University of North Carolina-Chapel Hill, Chapel Hill, NC 27514
PH- 919/966-5171
KW- (descriptive); Scope of program: Multi-state regional: SC, VA, and other southeast; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Information and referral; Consultation; Fee for I & R; Does charge a fee for consultative services; Fees for consultative services are not negotiable; Operational entire year (12 months); Description of focus of program: Physical medicine and rehabilitation; Other health related program focus: General medical evaluation with genetic and neurologic emphasis; Education; Vocational and career services; Vocational rehabilitation; Advocacy; Policy and planning, general; Does not publish newsletter regarding youth with disabilities;
KW- (topical); Handicaps/DD, general; Phenylketonuria; Adjustment/conduct disorders, behaviorally disturbed, deliquency; Attention-deficit disorders, hyperactivity; Learning disabilites; Central nerve system, Sense organ diseases; Genetic conditions; Mental retardation (incl. Downs);
AB- This is an interdisciplinary model providing primarily evaluation, recommendation and client-based consultation. The focus is on transition issues; general intellectual and behavior issues not having to do with transitions are usually seen in other programs at this Center. The care disciplines are Psychology, Education, Rehabilitation Psychology, and Medicine; others are available to consult. A wide range of client needs has been addressed by this team, including transitions from school to workplace, home to group home, and institution to group home.

UI-10255 - Programs/Projects
NM- Chicago Children's Diabetes Center
CT- Thorp Frank K., MD; Levitsky Lynne L., MD
AF- The University of Chicago - LaRabida Children's Hospital
AD- East 65th St. at Lake Michigan, Chicago, IL 60649
PH- 312/363-1975
KW- (descriptive); Scope of program: Statewide: IL, IN, WI; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Information and referral; Consultation; Teaching; Research; No fee for I & R; Does charge a fee for consultative services; Fees for consultative services are negotiable; Operational entire year (12 months); Description of focus of program: Hospital-based specialty care; Nutrition; Does publish newsletter regarding youth with disabilities;
KW- (topical); Diabetes mellitus;
AB- The Chicago Children's Diabetes Center provides comprehensive medical services for youth with diabetes from infancy to young adulthood. Emphasis is place on goals of individualized self-management of each child's diabetes with diabetes education based on the young person's developmental level and stage of cognitive development. During routine clinic visits, different topics are covered on each visit, at an age-appropriate level. Screening for long-term complications of diabetes is accomplished through physical examination and laboratory studies; early, aggresive intervention is instituted if abnormalities are found. A transitional care program is planned for adolescents with diabetes for uninterrupted medical care and support.

UI-10058 - Programs/Projects
NM- Adult Cystic Fibrosis Clinic & Support Group
CT- Bunten Barbara, LMSW
AF- Arkansas Children's Hospital
AD- 804 Wolfe Street, Little Rock, AR 72202
PH- 501/370-1100
KW- (descriptive); Scope of program: Statewide: AR; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Hospital-based specialty care; Social services;
KW- (topical); Cystic fibrosis;
AB- ACH Cystic Fibrosis Center follows CF patients of all ages, including adolescents and young adults. The CF team recognized that there are unique needs in this population. ACH has an "adult" clinic and luncheon for the adolescent and young adult CF on a quarterly basis. They are seen separately from the CF children. The clinic was so successful and met so many needs of the CF patient that an outgrowth of it was a monthly support group meeting for the adolescent and young adult with CF. Here the CF patient can visit with his peers and the CF social worker to discuss problems and issues associated with the transitional years (growing up, dating, sex, career choice, marriage, body image, death & dying) in a supportive atmosphere.

UI-10277 - Programs/Projects
NM- Adolescent Transition Program
CT- Carlin Ellen, M.H.A.
AF- University of Washington
AD- CDMRC-WJ-10, Seattle, WA 98195
PH- 206/545-1358
KW- (descriptive); Scope of program: Statewide; Population served: Urban; Suburban; Small cities/communities; Rural; Types of services provided: Direct service; Information and referral; Consultation; Teaching; Research; No fee for I & R; Does not charge a fee for consultative services; Operational entire year (12 months); Description of focus of program: Primary health care or hospitalization; Hospital-based specialty care; Does not publish newsletter regarding youth with disabilities;
KW- (topical); Chronic illness, general;
AB- The interdisciplinary team (physician, nurse, nutritionist, psychologist, social worker, project manager) will carry out program components: 1) promotion of transition program with University-based and community physicians; 2) patient/family education about the program; 3) patient/family selection and evaluation for transition; 4) patient health education and autonomy training;
5) assessment of the educational, vocational, family, and community service needs of patients and families; 6) identification of adult care providers who will take primary responsibility for patient care; 7) establishment of transition inpatient unit; 8) implementation of data management system;
9) professional education; 10) information dissemination; and 11) promotion of research.

CYDLINE Reviews

Please copy and share the contents of this publication. We ask that you credit the National Center for Youth with Disabilities as the source of information.

National Center for Youth with Disabilities/Society for Adolescent Medicine Coordinating Council:

Robert Wm. Blum, M.D., M.P.H., Ph.D.
Director, Adolescent Health Program
Minneapolis, Minnesota

Nancy A. Okinow, M.S.W.
Executive Director
National Center for Youth with Disabilities
Minneapolis, Minnesota

Gayle Geber, M.P.H.
Program Director
National Center for Youth with Disabilities
Minneapolis, Minnesota

Karen J. Stutelberg
Administrative Officer
Adolescent Health Program
Minneapolis, Minnesota

Donald Orr, M.D.
Director, Adolescent Health
Riley Children's Hospital
Indianapolis, Indiana

Dale C. Garell, M.D.
Medical Director
California Children's Services
Los Angeles, California

Lonnie Zeltzer, M.D.
Head, Div. of Child Development & Biobehavioral Pediatrics
UCLA School of Medicine
Los Angeles, California

Arthur B. Elster, M.D.
Director, Department of Adolescent Health
American Medical Association
Chicago, Illinois

Ex-Officio

Barbara Leonard, R.N., Ph.D.
Director, Maternal and Child Health
University of Minnesota
Minneapolis, Minnesota

Edie Moore
Administrative Director
Society for Adolescent Medicine
Granada Hills, California

Renee Jenkins, M.D.
President
Society for Adolescent Medicine
Howard University Hospital
Washington, D.C.

The University of Minnesota is committed to the policy that all persons shall have equal access to its programs, facilities, and employment without regard to race, religion, color, sex, national origin, handicap, age, veteran status, or sexual orientation.

National Center for Youth with Disabilities
University of Minnesota
Box 721 - UMHC
Harvard Street at East River Road
Minneapolis, MN 55455

Nonprofit Organization
U.S. Postage
PAID
Minneapolis, MN
Permit No. 155